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Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives

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ABSTRACT

Purpose: To examine the caregiving impact of those who support a family member with intellectual disability and epilepsy.
Methods: An online, qualitative international survey was conducted via the auspices of the International Bureau of Epilepsy with various stakeholders who support individuals who have intellectual disability and epilepsy. Qualitative comments were analyzed from respondents who identified themselves as family members ($n = 48$; 36%) who referred specifically to the impact of supporting a family member with these combined disabilities.
Results: Four main domains, which were comprised of ten themes, were derived from the qualitative data using Braun and Clarke's qualitative framework. These domains comprised (1) practical concerns, (2) disrupted family dynamics, (3) emotional burden and (4) positive experiences. In combination these themes illustrate the pervasive impact on family life for those supporting an individual with complex needs. Financial concerns, coordination and responsibility of care, diverted attention from other family members and social isolation all contributed a significant burden of care for family members. Positive aspects were, however, also cited including the closeness of the family unit and a fostering of altruistic behavior.
Conclusion: The study provides an insight into an under-researched area. The burden of caring for a family member across the lifespan has a largely negative and pervasive impact. Targeted service provision could contribute to an amelioration of the challenges faced by these families.

1. Introduction

A considerable evidence base exists documenting the increased prevalence of epilepsy among those with intellectual disability when compared with the general population.[1] For families caring for a child with intellectual disability, epilepsy carries a significant burden; it is the most frequently reported co-morbidity,[2] it is typically severe in presentation and refractory to treatment[2] and it is incrementally more prevalent and complex among those who have more severe levels of intellectual disability.[3] Epilepsy among this population is also associated with the presence of other lifelong conditions including psychiatric disorder[4] and autism spectrum disorder.[5]

The substantial burden of care for those supporting an individual with intellectual disability and epilepsy is reflected in increased attendance rates at inpatient, outpatient and accident and emergency facilities,[2] and at primary care where epilepsy is the most commonly reported presentation among those with intellectual disability.[6] While health care providers themselves are challenged to coordinate the multi-disciplinary support required by those with complex disabilities,[7] it is the family members of those with intellectual disability and epilepsy who carry much of the caregiving burden.[8] The financial impact for families supporting an individual with complex disabilities, for example, can be considerable given the additional costs associated with disability and the loss or earnings for those unable to take up employment

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due to their caring duties.[9–11] Somatic and psychological health, emotional health, quality of life and well-being have all been demonstrated to deteriorate among caregivers of those with complex disabilities.[12–14] There is also a time-related burden for family members who provide round the clock direct care support or for those who spend considerable time coordinating home-based care while they remain in the workforce.[7–9] In addition to the considerable responsibilities of caregiving, some families report that they are excluded from family and neighborhood activities which can further isolate them from wider social networks and supports.[8,15,16] Members of the public who unwittingly behave in an awkward, scared or embarrassed manner in front of those with disabilities[15] reinforce this sense of isolation and can arouse feelings of guilt and shame among family members.[14] Despite these many challenges, and although less commonly reported, it is important to note the positive benefits of caregiving, which include feelings of altruism and fulfillment of family obligation.[12]

As most children and a large proportion of adults with intellectual disability now live in the family home,[17] and given the increased prevalence and severity of epilepsy among this population,[3] it is timely to consider the impact of caring for someone who has epilepsy and an intellectual disability on the family.

2. Aim

This study sought to conduct an international survey via the auspices of the International Bureau of Epilepsy with various stakeholders who support individuals who have intellectual disability and epilepsy. The aim of this paper is to report on how the wider family is impacted where a family member, whether child or adult, has an intellectual disability and epilepsy.

3. Methods

3.1. The survey

An online survey was developed using the Bristol Online Survey Software[18] to examine the qualitative views of professionals, paid caregivers and family members who support people who have both an intellectual disability and epilepsy. The survey was anonymous requiring no demographic information from respondents other than whether they were over 18 years and were family members, paid caregivers or professionals. Respondents were also asked to indicate which country they lived in. Respondents were informed when reading the introductory material that by continuing to the survey they were consenting for their anonymized responses to be included in any subsequent analysis. Participants were given the option to exclude their direct quotes from being presented in any reporting of the survey.

The survey items comprised twelve open-ended questions exploring respondents' views on the needs of individuals with intellectual disability and epilepsy (see Box 1). The questions explored two key areas 'medical care and services' and 'the social impact of intellectual disability and epilepsy'. This paper reports on the latter area, the social impact (specifically drawing responses from questions 5–10), as findings relating to medical care have been published elsewhere (specifically responses to questions 1 and 2 in Box 1).[19]

Ethical approval for this research was obtained by the Research Ethics Committee of the School of Medicine at Cardiff University.

3.2. Sampling frame

The survey was distributed via a weblink to member organizations of the International Bureau for Epilepsy (IBE), the international umbrella body for national epilepsy associations worldwide, between July 2011 and July 2012. Due to the available resources of the research team, the survey was only distributed among countries where English was an official or commonly spoken language. Member organizations were invited to distribute the weblink to their members and to other organizations, such as those providing support to individuals with intellectual disability, using a snowballing process.

Box 1. Survey questions as presented in the online survey.

Medical care and services

1. What are your views on the diagnosis and medical treatment of people with epilepsy and intellectual disability? What are the problems? What helps?
2. What are your views on anti-epilepsy medications (including rescue medications)? What are the problems? What helps?
3. What are your views on services provided to support the care of people with epilepsy and intellectual disability? What are the problems? What helps?
4. Do you think there is enough information available about treatment, management and support for people with epilepsy and intellectual disability? Where do you look for this kind of information? Is it easily available?

Social impact of intellectual disability and epilepsy

5. In your experience how does having epilepsy and intellectual disability impact on getting and keeping employment? What are the problems? What helps?
6. In your experience how does having epilepsy and intellectual disability affect schooling or other forms of education? What are the problems? What helps?
7. In your experience how does having epilepsy and intellectual disability affect engaging in social activities and developing friendship groups? What are the problems? What helps?
8. In your experience how does having epilepsy and intellectual disability affect romantic relationships? What are the problems? What helps?
9. How do you think people with epilepsy and intellectual disability are seen by other people? Can this cause problems? Can this cause good things?
10. In your experience how does having epilepsy and intellectual disability affect family life? What are the problems? What helps?

Miscellaneous questions

11. In your contact with people with intellectual disability and epilepsy, have they expressed any particular views that are relevant to this consultation?
12. Is there anything you would like to tell us that you think is relevant to this consultation that is not covered by the questions above?

3.3. Participants

Fifteen national epilepsy associations, support groups and professional networks across seven countries consented to promote the survey either on their website and/or by distributing documentation to their members. Valid responses were obtained from 133 individuals in 13 countries. Half of all respondents identified themselves as professionals ($n = 67$; 50%), over one third were family members ($n = 48$; 36%), with the remainder identifying themselves as paid caregivers ($n = 18$; 14%). See Table 1 for a break down of family respondents by location. Although we did not explicitly ask for respondents to report the ages of the people they cared for, we were able to identify from the text that 24 (38.1%)

Table 1
Respondents by nationality.

Question	Responses
England	27
Ireland	11
Scotland	3
New Zealand	3
Malta	1
Canada	1
USA	1
Missing	1
Total	48

Table 2
overview of finalized domains and thematic groupings.

Domain	Theme
1. Practical concerns	1. Practical/logistical
	2. Control of epilepsy
2. Disrupted family dynamics	1. Split families and time pressures
	2. Social isolation of the family
3. Emotional burden	1. Stress and exhaustion
	2. All family relationship under pressure
	3. Experiences of stigma
4. Positive experiences	1. Close families
	2. Supporting others
	3. Changed perspectives

responses concerned young or school age children, and 8 (12.7%) responses related to adults. In the remaining 31 responses the age was unclear (49.2%), although in some of these responses the wording used is suggestive of younger children.

3.4. Data analysis

From a total data corpus of 1118 responses, which was comprised of the qualitative responses to all 12 questions listed in Box 1, a subset of responses were selected to constitute the data set analyzed in this paper. We had two key inclusion criteria for including responses from the data corpus in the data set for this sample. First, we selected all responses from those who self-identified as a family carer (444 responses in total). Second, we extracted those responses which explicitly referred to the impact on family life of some aspect of caring for a person with epilepsy and intellectual disability (including attending to any kind of medical need, managing problematic behavior, and other features of a person's disability that may limit their participation in 'ordinary life') (63 responses in total). Responses that dealt exclusively with the impact of epilepsy or intellectual disability on the person who had those conditions were not included in the data set for this paper as this was felt to extend beyond the research question.

These data were analyzed using the framework set out by Braun and Clark.[20] This framework proposes the analysis is commenced with extensive reviewing of the material. What followed was a process of initial descriptive coding, which was mostly conducted by RT, who took and inductive approach to coding the data from a realist/essentialist perspective. Initial coding was conducting by looking for reported experiences that described different aspects of the possible burdens that families were experiencing. Experiences that may contradict those burdens were also coded. These codes were then reviewed, redundancy was identified and removed, and the remaining codes were clustered into themes. Here we consider 'theme' to capture a feature of the data that respondents described as having an impact on the way they organized or experienced their lives. For example the control of epilepsy was considered to be a key theme as concerns around seizure control were described as impacting on the way families made decisions about how they organized their day to day lives. Once this initial work had been conducted a second author, MK, reviewed both the refined codes and the theme clusters and concluded that this analysis fairly reflected the data. These themes were then formalized and RT, CL and MK reviewed and refined the names of these themes to those that are reported in this paper, and grouped them under domains for ease of interpretation (see Table 2).

4. Results

Using the above criteria a total of 63 responses were included in this analysis (37 from Q10, 11 from Q9, 7 from Q7, 4 from Q5, 3 from Q8, and 1 from Q6). These responses constituted 14% of the total number of responses from family respondents. These data were coded to 59 initial codes. Removal of redundancy and the creation of additional codes to describe previously un-captured aspects of the data resulted in 54 final codes, which were then formally clustered into the 10 themes that form the basis of the findings discussed in this paper (see Table 2). Finally we grouped the themes into four broad domains to enable us to look at how these themes relate to each other (see Table 3 for code clusters);

(1) Practical concerns
(2) Disrupted family dynamics
(3) Emotional burden
(4) Positive experiences

The issues raised under each of these domains are presented below.

4.1. Domain 1 – practical concerns

Practical or logistical concerns were identified as being problematic in just under half of responses, and as such was a prominent domain identified within the data set. This domain comprised two main themes relating to (1) the practical impact of caring for a family member who has both intellectual disability and epilepsy (2) the specific impact of managing epilepsy.

4.1.1. Theme 1 – practical/logistical concerns

Meeting the day-to-day care and medical needs of a family member who has both an intellectual disability and epilepsy was a recurring pattern throughout the data. Many parents made reference to the incurred financial costs of supporting a child with a complex disability, and of the challenges they experienced in effectively managing their time. Some respondents suggested that their family member's care needs affected 'every aspect of life'.

> "It affects every part of family life, we are always aware of it, if we are not with her we have to make sure there is someone trained to look after her which has financial implications also, there are certain things we cannot do as a family such as holiday, attend certain events or even go to a restaurant as a family." (Response 13)

Caring for a family member with disabilities impacted significantly on the employment status of many family caregivers. A few parents described the difficulties they faced in maintaining employment given their caring role, and of the lack of suitable child care facilities that would enable them to remain in the workforce. Those seeking work experienced difficulties in sourcing jobs that accommodated their family member's care needs. These difficulties had clear financial implications for families.

> "Basically I have had to give up working outside the home as my son requires a great deal of care and with regular seizures and

Table 3
Clustering of themes and codes.

Domain	Theme	Codes
1. Practical concerns	1. Practical/logistical	'All aspects' [several families made a general comment that suggested their child's medical condition affected 'all aspects' of life]
		Finances
		Time
		Inability to find appropriate substitute care
		General practical/logistical issues
		Bureaucratic problems
		Reduced employment opportunities
		Requirement for careful planning
	2. Control of epilepsy	Meeting medical needs
		Unpredictability
		Good control of epilepsy helpful
		Epilepsy 'in background'
		Supportive professionals helpful
		Medication side effects
		Memory/personality changes
2. Disrupted family dynamics	1. Split families and time pressures	Split families
		Less time spent with other siblings (e.g. unable to attend school events, plays, sports days, etc.)
		Limited/no participation in social activities as family unit
		Parents sleep separately
	2. Social isolation of the family	Felt social isolation
		Non – accessibility of facilities
		Inability to attend big family/friend events
		Felt stigma – avoidance of some situations
		Behavioral problems – child with epilepsy
		Communication problems – child with epilepsy
		Unrealistic expectations in other people
3. Emotional burden	1. Stress and exhaustion	Tiredness
		Emotional burden of responsibility
		Stress
		Child feels guilty after an episode
		Anxiety about child's safety
		Concerns for the future
		Disheartening to see lack of progress
	2. All family relationship under pressure	Stress on parental relationships
		Arguments
		Keeping secrets
		Siblings perceive they receive less attention
	3. Experiences of stigma	Stigma – negative responses to child
		People staring at/make comments due to behavior
4. Positive experiences	1. Close families	General positive aspects
		Adapting as a family
		Close/loving family
		Family respond kindly to child
		'Few problems' [occasionally respondents indicated that they had few problems with care]
		Acceptance of/adaptation to limitations by siblings
		Personality shining through
		'Joy, not a burden'
	2. Supporting others	Meeting/helping other families
		Siblings more patient/considerate people
		Involvement in activism
		Developed empathy for others
	3. Changed perspectives	Realize what is important in life
		Less paranoid about development of normal siblings
		Grateful for what they have

illnesses I had to take a lot of time off when I was working." (Response 38)

"Financially, we have not been able to do some routine home maintenance such as fixing some broken tile-flooring due to the added expenses of caring for our daughter." (Response 12)

4.1.2. Theme 2 – control of epilepsy

Just under one third of respondents spoke of the difficulties they experienced in managing their family member's epilepsy and detailed the pervasive impact of seizures on family life. In particular, the unpredictability of seizures and associated safety concerns were a cause for concern.

"My daughter's epilepsy totally controls our lives. [...] My daughter cannot be left alone for long periods, despite having alarm systems in place and she usually does not get much warning that a seizure is coming on. [...]" (Response 24)

Several respondents spoke of how meticulous planning was required for family activities, and how these activities were typically restricted in scope to accommodate the person's disability.

"In our family, like others, having a child with epilepsy and ID[g] has significantly limited the things we do. We have to plan vacations carefully ensuring that the environment and local

[g] Intellectual disability.

health care facilities are appropriate for our daughter." (Response 12)

"It is difficult to do things spontaneously – everything has to be planned." (Response 19)

Effective seizure management through epilepsy medication resolved some of the challenges.

"Because the medication is stable, there are few problems, going on holiday means sometimes requesting use of fridge to store the yoghurt for the medication, for instance." (Response 14)

4.2. Domain 2 – disrupted family dynamics

Codes relating to disrupted family dynamics were identified in just under a third of responses. Two themes in this domain explored the impact of having a family member with intellectual disability and epilepsy on the family dynamic; (1) the splitting up of the family and reduced time for interpersonal relationships and (2) the social isolation of families who care for a person with a complex disability.

4.2.1. Theme 1 – split families and time pressures

Respondents frequently reported being unable to go anywhere as an entire family unit, and being unable to spend as much time as they would like with siblings and their spouses. Instead, the family unit was frequently split, with one parent spending a lot of time with the family member with epilepsy, while the other parent spent time with siblings. As a child with epilepsy may have medical needs that are unpredictable and may therefore disrupt family events, some parents reported that at times they felt they were unable to optimally support other siblings.

"[. . .] We tend to split up as a family – one parent with [Child's name], one with our 2 boys so that they can still take part, [. . .] (Response 2)

"[. . .] As seizures can be stress-related, if we plan to do something (e.g. holiday, day out, etc.) she can become anxious due to the change and bring on seizures, so activity can be hit & miss. Have had to cancel outings at last minute many times. This has affected lots of things we have wanted to do with our son over the years as well, so sometimes we have not both been able to support him, either myself or my husband does an activity with my son, whilst the other looks after our daughter. [. . .]" (Response 5)

Some respondents also reported that the parental relationship was neglected to the extent that partners frequently did not have time together alone, and in some cases were unable to sleep in the same bed together due to concerns over their child's nocturnal seizures.

". . . Due to nocturnal seizures and sleep disruption, my husband and I take turns sleeping with our daughter and hence, never sleep in the same bed, We rarely go out on "dates" because we don't want to take advantage of family members who already help us out on a regular basis. . ." (Response 12)

4.2.2. Theme 2 – social isolation of the family

Respondents reported that they found themselves increasingly socially isolated when tackling some of the practical difficulties they face. The challenges associated with problematic behaviors occurring in public places, poorly controlled epilepsy and inaccessible facilities resulted in many families choosing not to engage in public social events, extended family events or other recreational activities.

"It causes a lot of difficulties for us as a family as it puts a huge strain on the family when our daughter is ill and in status we cannot leave the house for days at a time or else protracted stays in hospital all affect the normal family day to day existence." (Response 16)

"As a mother I don't even have a social life or friends." (Response 46)

Problematic behavior, and the practicalities of managing these behaviors in public, prompted some families to withdraw from socializing in public places, and caused difficulties in securing childcare.

". . .We avoid social outings which involve large crowds or other highly stimulating environments due to risk of seizure trigger or emotional melt-down. . ." (Response 12)

"It is difficult to get someone confident enough to mind her. She has temper tantrums like a toddler and can be extremely difficult to cope with. It has had a very negative effect on family life." (Response 17)

4.3. Domain 3 – emotional burden

This domain explored the emotional burden facing those who support a family member who has intellectual disability and epilepsy. Descriptions of the emotional impact of caring for a child with complex disability were identified in just under half of the responses in the data set. Three themes were identified (1) stress and exhaustion and (2) pressures on interpersonal family relationships and (3) experiences of stigma

4.3.1. Theme 1 – stress and exhaustion

Respondents vividly described how their efforts to optimally support a family member with complex disabilities were frustrated by finances, social isolation and unhelpful bureaucratic systems, all of which took an emotional toll on family life. The burden of the responsibility of caring for a child with complex needs was also a considerable stressor. Responses about the impact of practical and logistical issues on respondents emotional life was the most frequent theme identified from responses in this domain.

"Emotionally both my husband and I are worn down. Life can never be anywhere near what we would like it to be. All the difficulties that epilepsy and ID bring are ceaseless. Added to this are several formal complaints against our local Social Services (upheld), the SEN[2] Tribunal and DLA[i] Tribunal (we won), I resent having had to battle for what should have been offered without question." (Response 7)

Other respondents expressed anxieties regarding the safety and vulnerability of their family members, both with respect to the possibility of them having a seizure in an environment where they were unable to gain medical assistance, and to the possibility of these individuals being vulnerable to abuse. The demands of taking responsibility for a child with complex care needs were also highlighted by a few parents.

[2] h Assessment for SEN (special educational needs) is a UK government process that can lead to specific extra support in educational settings (https://www.gov.uk/children-with-special-educational-needs/assessments).

[i] DLA (disability living allowance) is a UK social benefit to support children who have extra care needs (https://www.gov.uk/disability-living-allowance-children).

"It is a major worry because we don't [know] the hour or the day, we are doing normal things one minute and the next we are waiting on an ambulance. We try to be normal as possible but it's always on our minds is she ok [?] If we text her and get no reply or if she doesn't answer her phone, . . ." (Response 19)

"As a carer, you have to take full responsibility, for meds, safety, she is not capable of taking responsibility, or knowing danger." (Response 3)

Aspirations and worries for the future were reported by a few participants, especially where parents perceived a lack of development as disheartening.

"My son just started school, about 9 months ago, a school for children with special needs, I am waiting, hoping and longing for a positive change in my son. When he will be able to communicate with me, express himself and he will stop using diapers, he cannot walk long distance so I push him round in a buggie." (Response 63)

4.3.2. Theme 2 – all family relationship under pressure

While a relatively less frequent theme in the data, descriptions of interpersonal relationships under pressure were a prominent worry. The emotional stress and exhaustion experienced by these families strained parental relationships and created tensions on the wider family dynamic. In particular, parents reported arguments amongst themselves, and that their relationship with siblings was less than optimal as attention typically focused on the child with epilepsy.

"Causes a lot of stress between myself and my husband. When my daughter is being particularly difficult it can cause big arguments." (Response 5)

"My older son has felt over the years that he doesn't get treated fairly as my daughter needs so much time and attention. He is now a teenager and understands better but at the time it was hard to explain or split the time so both got the love and attention they [. . .]." (Response 25)

4.3.3. Theme 3 – experiences of stigma

Another source of emotional distress was described from beyond the confines of the family. Some respondents spoke of how they had endured negative reactions from the public, and how they had experienced acts of discrimination and instances of stigma within the wider community. Respondents reported how individuals would stare at their family member, would refuse to engage with them or would make unhelpful comments about their behavior.

". . .people look at you in a funny way. Some people make side comments people who don't understand what you are going though, it is hard enough to have a child with epilepsy and intellectual disability, he is not at fault and he did not ask to be born that way." (Response 46)

". . . engaging in social activities outside of our immediate family and friends is fraught with tension and worry as people stare at my daughter and are almost afraid of her. [. . .]" (Response 45)

4.4. Domain 4 – positive experiences

Positive experiences were mentioned in just under one third of responses. We identified three relevant themes; (1) their experiences of closeness within their family unit through their support of a family member with disabilities (2) opportunities to support and educate others (3) their amended priorities in what was important in life.

4.4.1. Theme 1 – close families

Within responses describing positive aspects of caring for children with epilepsy and intellectual disability, the predominant theme was that of the benefits of close and supportive families in which children's personalities and qualities could develop. Some parents spoke of the joy that their children bought them, and were pleased when their children were able to express their own personalities. Others commented on the harmony gained by families as they adapted to accommodate a family member with disabilities. They described how they had fostered a close family dynamic and derived satisfaction that their child appeared happy.

"Of our 4 children, the 2 younger ones have disabilities and still live at home. As they have always been on the autistic spectrum, it is our normality and we just work around it. No one knows how our family life would be had things been otherwise. They are a real joy and not a burden. There are a number of activities we can all enjoy together." (Response 27)

4.4.2. Theme 2 – supporting others

Occasionally respondents reported how siblings had benefitted from having a family member with disabilities. Parents described how these siblings grew into patient, open minded and empathetic people who were knowledgeable about epilepsy in particular, with some becoming active members of epilepsy campaigns.

"I think it has made us, her parents and her siblings, more tolerant and understanding of her and other people's difficulties, and grateful for what we have got. [. . .]" (Response 11)

"[. . .] We have had the opportunity to participate in the advocacy community and have been able to help other families who are experiencing the same difficulties we are." (Response 12)

4.4.3. Theme 3 – changed perspectives

Two families reported that having a child with epilepsy and intellectual disability had altered their perspective, such that they appreciated the small things in life and were able to prioritize things that were truly important. While this was a minor theme within the data, the responses were eloquent about this benefit, and worth noting here.

". . .There are some good things: we have learned to appreciate the small blessings in our life that we might otherwise take for granted.[. . .]" (Response 12)

5. Discussion

This study has provided insight into the experiences of families caring for a family member who has both epilepsy and intellectual disability. Four key domains were identified: practical concerns, disrupted family dynamics, emotional burden, and positive experiences.

We consider the domains identified from the data as being inter-related such that logistical or practical difficulties may affect how families organize themselves and their time, and the opportunities they have. The impacts appear to be wide ranging, effecting the way in which families plan their day to day activities, the places they may choose, or not choose to visit, their ability to act as one cohesive family unit, and their ability to predict what

they may or may not be able to do in the short or long term future. These arrangements appear to impact on the other three domains. For example, where epilepsy control is particularly poor or seizures are unpredictable, families may respond to this by splitting the family. As a result parents may spend less time with siblings and their spouses, which may in turn inflate emotional pressures on the interpersonal relationships involved.

Whilst research has shown epilepsy to be common,[22] and associated with chronicity, severity and increased mortality in people with an intellectual disability[1,2], less attention has been paid to family experiences of the care burden[21]. Research has focused on specific epilepsy syndromes; Lennox Gastaut[23] & Dravet.[16] Our research supplements this picture; control of epilepsy was mentioned in just under a third of responses in the data set. Poorly controlled epilepsy was described in a number of responses as disruptive to the day-to-day lives of the entire family, and both the unpredictability and the possibility of hospitalization were identified as key sources of worry to these families. This is consistent with other research among children with different types of epilepsies (e.g. TLE, JME).[24,25] For families where active epilepsy was reported as disruptive, we identified key concerns relating to seizure risk and the burden of bearing responsibility for treatment delivery. For other families epilepsy was not identified as a key concern and other stresses were identified from the data, such as behavioral problems, general logistical concerns, unkind responses from the public and a perceived lack of support from friends, family or external agencies. Co-morbid behavioral problems were a smaller theme in the data, but where present were of particular concern to the respondents. This finding concurs with the work of Smith and Matson, who found that children who had intellectual disability with comorbid epilepsy and autism spectrum disorder had poorer social skills than children with intellectual disability alone.[26]

Our data provides a cross sectional snapshot of what families were experiencing between summer 2011 and 2012. However we can speculate that the stresses on these families are complex and may fluctuate over time. Given the nature of complex disabilities such as the combination of epilepsy and intellectual disability, it is likely that an individual will have greater care needs as some times in their life course than others. This could place differing demands on their caregivers at different times. This may lead to intermittent stress on the interpersonal relationships that make up the family unit, perhaps on different sets of relationships at different times, thus resulting in different burdens family life at different times.

The concerns of families over stigma are consistent with those seen in families of children with epilepsy.[27] Families reported a range of potential discrimination with facilities being inaccessible to people with disabilities or ill-equipped to deal with a seizure, and in the reaction of other people, who are not always kind. Some respondents reported that their child was ignored or patronized, stared at, that their behavior was openly disapproved of, or that their child had been called names or physically abused, which coincides with the findings of Gray, who looked at the experiences of parents of children with Autism.[28]

Almost one third of respondents reported some positive aspects of caring for children with epilepsy and intellectual disability, including close supportive family dynamics, a role in educating others about epilepsy, and new perspectives toward what was important in life. A fruitful line of research may be to conduct further detailed research with families who show such resilience in this area in order to identify what factors facilitate such resilience.

5.1. Strengths and limitations

A strength of the study has been its ability to look at a broad range of experiences of family caregiving. When research has looked the practical burdens of families caring for younger children with an intellectual disability and epilepsy, an impact on financial status, exhaustion and employment is identified.[9,11] Our research is consistent with this previous understanding, particularly in the emergence of co-morbidity (behavior disorder, epilepsy, pain) as a contributory factor to the burden that families who care for someone with epilepsy and intellectual disability face.

This study has several potential weaknesses. First, is whether the data is representative of the population being addressed. Recruitment was purposive and thus cannot be seen as an epidemiological sample. Second, while we distributed the survey internationally, the respondents who self identified as being family carers were predominantly from the UK, and so the data here is not an internationally representative sample. Third, we did not systematically collect data on a number of demographic dimensions as we wished to encourage participation as widely as possible. We did not collect data on the age and number of children and adults in the household, how many children may have a disability, may have comorbid conditions and the severity of the disabilities involved, the financial resources available to the family, schooling or employment status. As a consequence we cannot look at how different types of responses may relate to these demographic variables. This kind of detailed research would require in depth qualitative interviews. The aim of this study was to sample those with a specific interest and experience in the issues, and specifically in this paper, the views of families themselves. In an attempt to reduce the possibility of too narrow a sample, multiple sources were used to identify families in multiple countries through charity organizations who work directly with caregivers. While we are unable to claim this sample is representative of the views of all families caring for a child with epilepsy and intellectual disability, for a qualitative study this sample is relatively large and achieved saturation in themes within the responders.

6. Conclusions

Caring for a child with complex care needs has an impact on the family as a whole, imposing practical restrictions and emotional complications on their lives. Professionals supporting this group can take an active role in reducing this burden, both in relation to the daily management of people with intellectual disability and epilepsy, and in directing the much-needed development of services. High quality seizure control and epilepsy services that are tailored to the needs of families would be an important factor in reducing this burden. Other supports would involve improved care support such as specialist training for child care providers in seizure care and effective signposting of other services that may provide financial and care support.

Conflict of interest statement

The authors report no conflict of interest.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.seizure.2014.07.005.

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